

Our Accomplishments: Improving and Expanding Care Options for the End of Life



For more than 40 years, by using a comprehensive strategy including legislative advocacy, grassroots organizing, media outreach and litigation, Compassion & Choices, the Compassion & Choices Action Network and our predecessor organizations have led most of the significant advances in the movement to expand and improve end-of-life care options. This includes:

Advance Care Planning and End-of-Life Support

Compassion & Choices is the leading advocate for making important healthcare plans in advance and developing patient-centered end-of-life care tools. Compassion & Choices:

- Developed the first national end-of-life consultancy program in 1993, which offers patients and their families tools, information and emotional support on the full range of available end-of-life care options.
- Pioneered the use of advance directives and transformed them from strictly legal documents to a values-based approach for communicating end-of-life care priorities.
- Developed a dementia provision for advance directives, and created one of the earliest and most widely disseminated toolkits to help translate people's values

into care preferences if they get a dementia diagnosis.

- Deployed numerous resources for how to navigate end-of-life care planning amid the COVID-19 pandemic.
- Advocated for the successful adoption of a new Centers for Medicare and Medicaid Services rule, allowing the agency to reimburse doctors for engaging in advance healthcare planning discussions with patients.
- Helped secure critical provisions in the Coronavirus Aid, Relief and Economic Security (CARES) Act, including improvements to telehealth laws, ensuring safe and equitable access to care for terminally ill patients without the health risks of in-person visits.
- Commissioned a peer-reviewed research scan about disparities related to end-of-life care and planning, and used this research to frame a 2021 summit between end-of-life care experts. This research and resulting summit report is used to identify and eliminate barriers to accessing palliative care, hospice and end-of-life care planning in historically disadvantaged communities.
- In a landmark settlement of a federal lawsuit we filed in Idaho, *Almerico v. Denney* (2018), we successfully challenged the pregnancy exclusion in Idaho's advance directive law. The court held that Idaho's law violated an individual's constitutional right to refuse unwanted

medical treatment. The resulting settlement required Idaho state officials to create a new advance directive template without the pregnancy exclusion.

- Filed an amicus (friend-of-the-court) brief in *Full Circle Living and Dying v. Sanchez* to underscore the importance of death doulas in furthering patient-directed care.
- Helped secure a victory in *Greenberg v. Montefiore*, a New York case about whether an individual can recover damages when a doctor provides unwanted medical treatment in direct contravention of an individual's living will or designated health care proxy instructions.

Palliative Care and Pain Management

Compassion & Choices stands at the forefront of championing patient rights and appropriate care for the end-of-life. Our organization:

- Legitimized palliative sedation as a recognized medical practice by advancing the U.S. Supreme Court case, *Vacco v. Quill* (1997).
- Established the undertreatment of pain as a form of elder abuse and that caregivers must manage patients' pain in a California court case, *Bergman v. Eden Medical Center* (2001).
- Increased physician training in palliative care in California by working with the California Medical Association to advance Pain Management and the Appropriate Care and Treatment of the Terminally Ill in California (AB 487) in 2001. The law requires most California-licensed physicians to take, as a one-time requirement, 12 units of continuing medical education on pain management

and "the appropriate care and treatment of the terminally ill."

- Helped enact requirements that healthcare providers share information with patients on end-of-life care options. Compassion & Choices sponsored and helped pass the Palliative Care Information Act in New York (2010) that requires healthcare workers to provide information and counseling on end-of-life care options and the Right to Know law in California designed to ensure that patients can receive information about all of their legal end-of-life care options.
- Filed an amicus brief with the United States Supreme Court in *Ruan v. United States* (2022) detailing the importance of individuals having access to adequate pain medication at the end of life.

Medical Aid in Dying

Compassion & Choices, the Compassion & Choices Action Network and our predecessor organizations have led or contributed to the advancement of medical aid in dying across the country.

- Compassion & Choices founder, president emerita and senior adviser, Barbara Coombs Lee, co-authored Oregon's landmark Death With Dignity Act, which went into effect in 1997. Decades later, lawmakers continue to look at the Oregon experience and are developing new legislative approaches to authorizing medical aid in dying nationwide.
- We pioneered the model of medical aid in dying that helps ensure doctors can ethically practice in an open, legitimate and accessible way, and integrates the option into patients' end-of-life care. A major achievement of our advocacy work was the publication of clinical criteria in the

Journal of Palliative Medicine in December 2015.

- We advanced the historic end-of-life care court case, *Glucksberg v. Washington* (1997), to the U.S. Supreme Court. While the Court declined to recognize a federal constitutional right to medical aid in dying, the landmark ruling by the nation's highest court encouraged individual states to engage in an "earnest and profound debate about the morality, legality and practicality of" medical aid in dying, setting the stage for the consideration of such legislation at the state level.
- We led or contributed to efforts to authorize medical aid in dying in 11 jurisdictions: Oregon (1994, ballot initiative), Washington (2008, ballot initiative), Montana (2009, state Supreme Court decision), Vermont (2013, legislation), California (2015, legislation), Colorado (2016, ballot initiative), Washington, D.C. (2017, legislation), Hawai'i (2018, legislation), New Jersey (2019, legislation), Maine (2019, legislation) and New Mexico (2021, legislation).
- We have intervened in or submitted amicus defending medical aid in dying in a number of opponent challenges to medical aid-in-dying laws. These cases include, *Ahn v. Hestrin* (California), *CMDA v. Bonta* (California), *Glassman v. Grewal* (New Jersey), and *Vermont Alliance for Ethical Healthcare v. Hoser* (Vermont).

Compassion & Choices and the Compassion & Choices Action Network made the following improvements to medical aid-in-dying laws:

- In 2015, we partnered with Patient Choices Vermont to successfully remove the sunset clause from Vermont's medical aid-in-dying

legislation and establish a reporting system to record the use of medical aid-in-dying at the state level.

- In 2019, we successfully advocated for an amendment to Oregon's Death with Dignity Act that allows providers to waive the 15 day waiting period for terminally ill patients who want to use medical aid-in-dying if they are unlikely to survive the waiting period.
- In 2021, we led the campaign to improve California's End of Life Options Act by decreasing the mandatory waiting period from 15 days to 2, and requiring healthcare systems and hospices to post their End of Life Options Act policy on their websites to increase transparency.
- In 2022, we worked with our partners at Patient Choices Vermont to amend the state's medical aid-in-dying law to allow patients to request medical aid-in-dying medication using telehealth, pharmacists and other medical professionals. Additionally, we eliminated a provision that required a mandatory 48 hour waiting period between the final request from the patient and the physician's ability to write a prescription.
- We set the stage to improve access to medical aid in dying across state lines by filing a federal lawsuit in Oregon, *Gideonse v. Brown* (2021). This lawsuit challenged the residency requirement for medical aid in dying under Oregon's Death with Dignity law. As a part of the resulting settlement, Oregon authorities agreed not to enforce the state residency restriction for medical aid in dying and to urge the state legislature to formally remove it from the law. Building off our victory in *Gideonse*, we filed a lawsuit, *Bluestein v. Scott*, challenging the residency

requirement in Vermont's medical aid-in-dying law in August 2022.

Compassion & Choices and the Compassion & Choices Action Network continue to defend the right to access medical aid in dying. We protected:

- The Oregon Death With Dignity Act in court against two challenges, one from the National Right to Life group and one from the U.S. attorney general.
- The right to use medical aid in dying in Montana against five legislative attempts to overturn the Supreme Court ruling.
- The Washington D.C. Death with Dignity Act against three congressional efforts to repeal the act in 2017, 2018 and 2019.
- The right to use medical aid in dying in Vermont against multiple attempts to repeal or weaken their legislation.
- The California End of Life Option Act against two separate lawsuits, one of which is still pending.
- The New Jersey Medical Aid in Dying Act against attempts to overturn it in the state legislature and in the courts.

To learn more about the history of the end-of-life choice movement, please visit our website at CompassionAndChoices.org/resource/history-end-life-choice-movement/. While much has been accomplished, Compassion & Choices will continue our work until the full scope of end-of-life options is available to all Americans.